


**Dr Joanna Zakrzewska**

Barts and the London  
Hospital  
Queen Mary's School of  
Medicine and Dentistry

**Job title:**

Senior Lecturer/ Honorary  
Consultant

**Specialty:**

Oral Medicine

**Innovation: Set up, together with a patient, the UK Trigeminal Neuralgia Association (TNA) Support Group**

Trigeminal neuralgia is a rare form of facial pain which causes severe electric shock like pains to the face. "Although it is rare, it affects 0.1 per 100,000 people, other forms of facial pain are not uncommon," says London consultant Joanna Zakrzewska. "Patients feel extremely isolated, as they have never met anyone else with the condition so we set up this organisation to help patients meet fellow sufferers in person, through the chat rooms set up on the web or by a telephone helpline."

The support group began two years ago and this summer, 2001, formally became an association applying for charity status with around 300 members. It was originally funded by donations from "grateful patients" but now raises money through subscriptions and industry donations.

Dr Zakrzewska says: "In my own practice I see around 500 patients a year with facial pain of which around 25 are newly diagnosed patients with trigeminal neuralgia. One of my patients, Elisabeth Boulot, went to the US to have treatment and came back willing to set up a group in the UK. The first meeting took place at Barts in 1999 and was attended by 50 people.

"With the support of the US TNA group we gradually built up the organisation and Elisabeth Boulot has now gone back to France where she is hoping to set up a French equivalent. In her place we now have another of my former patients Carole Straker."

Both the US and the UK associations are run by patients and have a medical advisory board to help them. Dr Zakrzewska is chairman of the UK medical advisory board. She says: "We also have a group of healthcare workers from a wide variety of specialities including neurosurgery, neurology, pain, psychology, oral medicine, dentistry and psychiatry to help with patients' queries and give them both written and verbal information.

"The patients are no longer isolated and have more information in order to gain optimal treatment. Since January 2000 the UK website has had 22,142 visitors."

Dr Zakrzewska wishes she had more time with patients and more resources. She says: "Patients with chronic pain need to be listened to, need a full explanation of their problem and how it can be managed so they can be put in control. If we had more time to spend with patients it would improve patient compliance with treatment, reduce unnecessary referrals and improve patient satisfaction."

And she adds that although an increase in NHS money has enabled her to have clinic computers and introduce electronic patient records she needs to set up a multidisciplinary facial pain clinic and more than four clinics a year for patients with trigeminal neuralgia.

"I was initially an NHS consultant but, in the last five years I have become an academic teaching medical and dental students and doing research. Lack of funding and recognition for clinical research is very frustrating. Despite a record of high quality research in trigeminal neuralgia I cannot get funding for simple projects."

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